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Socialization and Interdependence

PETER LINDSAY
SHIRLEY MCNAUGHTON

We couldn't think of a better way to relate to the theme of independence, interdependence, dependence and socialization than by asking individuals who have a special reason to feel strongly about these matters to speak for themselves. Tanis Doe, Kari Harrington, Nola Millin, Paul Marshall, Michael Williams and Andrew Murphy do just that.

Tanis Doe focuses upon equality and the acceptance of diversity. How supportive her presentation is for we two educators who have always valued the *differences* of our students and felt great concern regarding the limited opportunities of those with severe disabilities. How eloquently she questions assumptions that everyone must be helped to become "normal." We thank her for her interdependent model of living.

We also thank her for providing a living example of the difference between one who is handicapped and a situation that handicaps one. Peter will always have a lasting impression of Tanis Doe standing on a stage, leaning slightly on a cane and peering into an audience through bright television lights. She was preparing to make a speech at the Independence 92 Conference, a stimulating international conference, organized and operated by individuals with disabilities that was held in Vancouver, Canada in the spring of 1992. Tanis noted that, unlike her usual world view, at this moment she *felt* handicapped. She was having difficulties with failing eyesight, and the bright television

lights shining on her made it impossible to read her text. Her option of using braille was ruled out: Since she is deaf, she needed both hands to sign her presentation. It was painful for her to stand and she needed an aid. But the organizers had suggested she should stand so that the audience could see her, especially those who were reading her signing directly.

It was a powerful and compelling demonstration of an important message: In most cases, it is the situation that *handicaps* the individual. An individual is not inherently "handicapped." It is the situation that makes him or her feel handicapped. In spite of the *handicapping situation*, Tanis gave a compelling and important presentation on independence and interdependence, the essence of which is presented in this issue.

The Changing Times

We are in the midst of dramatic world-wide social change with many individuals and groups striving for independence. The results of their struggles can be seen politically in the disintegration of large unions of former politically independent constituencies which were brought together as a result of previous military conquest. People all over the world are no longer satisfied with allowing some remote central authority to determine their lifestyle or decide on what is important for them. People want local autonomy — the right to decide one's own destiny.

The same theme is being played out in the disabled community. Sometimes it appears in the form of "profession bashing". Individuals no longer wish to accept blindly the right of professionals to decide

important life issues for them. It does not matter whether that professional is an educator, a medical doctor or a clinical service provider. Individuals want to determine the direction of their own lives. "Self help" groups are springing up in all disability areas to challenge the right of the pre-existing professionally based groups that have dominated the field before. Important questions arise. Who should decide what assistive aids a person needs or should have or what is the most appropriate living arrangements for a particular individual?

Professionals are being challenged to meet the changing views of those with disabilities, with changes to the professional role. If the relationship has previously been one of child to parent, then the same struggle lies ahead that every child and every parent goes through, as the child grows towards maturity. Why should this process be different for individuals with disabilities? What is the most appropriate role for the professional to play in this new era?

Associated with our growth towards independence is our growing need for satisfying social relationships outside the family. Achieving independence without satisfying our interdependent social relationships would be a hollow victory indeed. We need to be part of a congenial social network as well as have control over our own destiny. For individuals who require physical assistance, relationships with others take on a new dimension. These are the issues we attempt to relate to in this **Communicating Together**.

You will notice that Jeff Higgenbotham and his colleagues are taking a holiday. In their place, we are fortunate to have news of Ontario's first Computer Olympics.

We would also like to draw your attention to a piece that appears in our *Readers' Write* section which may be unsettling but which nonetheless needs to be considered. Carol Lynn Katsios' concern provides an interesting corollary to Tanis Doe's "But we are all human!" Regular readers of **Communicating Together** will know Carol Lynn Katsios as one of our Associate Editors who always provides a sensitive view of the problems faced by consumers. For this issue, Carol Lynn has submitted a Letter to the Editor from her summer home in British Columbia. She raises a provocative and difficult issue for all of us who support consumer's rights, but one that we feel should not be hidden away. Our concern for the vulnerability of and the inequities faced by those with disabilities must not cloud our vision and cause us to overlook the vulnerability of *all* persons. Carol Lynn helps us realize the challenges that we *all* face.

Introducing Paul's Place

We're very pleased to welcome a new Associate Editor and announce the beginning of a new section starting in the December Issue. Paul Marshall is joining our group of editors. His section will be called **Paul's Place** and we hope you will enjoy dropping in during the year! You'll get a glimpse into Paul's thinking from his *Perspective* in this issue.

We had the opportunity to get to know Paul as a very capable colleague during the recent ISAAC Conference and were delighted when he responded positively to an invitation to join our editorial group. Paul serves on the ISAAC Board of Directors as a representative from Canada. He participated in a consumer panel during the recent ISAAC Conference in Philadelphia. He also attended the ISAAC Conference in Stockholm in 1990. Back home, Paul volunteers at the Yonge Street Mission in Toronto and each week spends time with young people who need help in tackling their life situations. We hope *Paul's Place* will provide the forum for

AAC users to *talk things over* with Paul within **Communicating Together**. We urge you to write to Paul care of **Communicating Together**!

Kari and Ruth Harrington continue to welcome your full length contributions for the *Living* section. We wish to provide many formats for consumer views.

A New Publication Series

We have come to the conclusion that there are a considerable number of manuscripts that are important to the AAC field but for which currently there is no suitable publication outlet. They may be unsuitable for publication in ISAAC's AAC journal or other ISAAC affiliated publications because of length, subject matter or informal style. We would like to provide a publication outlet for such materials within an informal publication series.

Types of material: The types of material that would be suitable for this program would include such things as extended case studies and assessment protocols. The style of writing should be informal and communicative but follow American Psychological Association referencing style. Consistent with the basic philosophy of **Sharing to Learn**, the material should focus on issues dealing with the human impact of AAC.

Turn around time: One of our goals is to make the publication of this sort of material as timely as we can. To keep the turn around time as short as possible, we will attempt to review the manuscript and make a decision on its suitability for publication within a maximum of 30 days from receiving it. We will attempt to publish the manuscript within 30 days of deciding on its suitability. To meet this schedule, we would very much appreciate receiving the manuscript in either IBM or Macintosh disk format.

Price: Since a primary goal of the publication program is to make

the material as accessible to the field as possible, we want to keep the price as low as we can. Thus the price will be set to recover the production costs (e.g., copy editing, layout, etc.) over the sale of the first ten copies, the reproduction and binding costs, the mailing costs and a modest handling fee. The author will receive a royalty of either 10% of the sale price or \$1.00 per copy whichever is larger. According to this pricing, structure, we expect that a manuscript of 50 pages would sell for approximately \$15.00 US.

Procedures for submission: If you have a manuscript you think is appropriate, please send to **Sharing to Learn** your name, address, the approximate number of double spaced pages (8 1/2 by 11), and a brief description of the manuscript.

We have some materials available now (see page 8). If you are interested in purchasing any of them, watch for an order form in the next issue.

Sound Tapes

At this time, we will not be producing sound tapes of the articles in **Communicating Together** that we talked about in the last issue. We received only one request and tapes are too costly to produce unless there is a demand for a larger number.

Next Issue

The theme for the next issue of **Communicating Together** will be *Facilitated Communication*. We look forward to presenting several views on this topic along with some of the associations it has brought to mind — more on independence; the framework for evaluating our field's progress presented at David Beukelman's opening address at the Research Symposium associated with ISAAC; the manufacturer's role in guiding technical development and clinical practice; band wagons; terminology and what we do with it!

See you in December.

Peter & Shirley
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INDEPENDENCE: A DEFINITION THAT LIBERATES

TANIS DOE



As a woman with several disabilities I have integrated many different ideas about equality and reached an understanding of how I feel I want to fit into the rest of the world. This view of equality takes into consideration that I am not only a woman, but a mother. I am not only deaf but I have physical disabilities. I not only have severe medical problems but I have emotional needs too. And my daughter is not only a deaf girl but is also a Black immigrant from Jamaica. She is not only adopted but is adopted by a single mother who is often sick, always studying and never living above the poverty line. So, my personal experience, and my political affiliations which are left-leaning and extremely feminist (but I have no membership cards to prove that — it is all quite personal and academic) integrate issues of race, gender, family status, age, disability, health, class and nationalism. I can't predict what will happen to me or to my daughter, and it is this unpredictability that has influenced my understanding of equality. We are always changing and as individuals and cultures we will never ever arrive at an end because we are living growing beings.

Equality as the Goal

In the movement of people with disabilities, we often describe our allies as the equality seekers. We use the term equality in many ways to describe laws, rights and opportunities. There are many different measures of equality including equality of results, equality to benefit, equality of opportunity and equality in representation. We have many different uses for the word equality but basically we hold equality up as a goal. It is something we want, and will work towards by removing barriers. Yet, it is something that we do not explicitly define or visualize in isolation. We refer to barrier-free environments, removal of obstacles, accessibility, accommodation and integration but we do not often describe what equality is, or would be for us. So we are being given a chance today. To define equality.

I am not entirely convinced that we would recognize equality if we found it, or that we haven't found it and overlooked it. But I do know that I will continue to work towards living in a world that accepts and values diversity as much as it currently does conformity. In this vision of equality, power will be given to the individual and not to institutions. This introduction is meant to demonstrate that my position is not to give the "The answer" or "The definition" that should be adopted. Rather it is one woman's definition that is based on lived experiences and beliefs. I want to dedicate it to my daughter — Ann-Marie. I hope she finds equality.

Equality with What? For Whom? To Whom? More Questions

To define equality as a concept, or to set our collective sights on equality we need to know the players. If equality involves "comparable standards or results" then we need to know what we are comparing — apples and oranges, men and women, meat and soya beans, people with disabilities and . . .

Do we want equality for people with disabilities that will make us "equal" to people without disabilities? Do we want all people with disabilities to be equal to each other? Do we want people without disabilities to be equal to us? Which people do we want to be equal to? The white men with jobs? *No Please!* Shall we stress the similarities or our differences? Will we accept the dominant value of independence from the help of others? Or will we question the value system which devalues dependence on other people? Is being a person with a disability so enlightening and wonderful that all people should join us in our experience? Or is being able-bodied (or even able-minded) so desirable that we should cast off our burdens of deviance and become normalized — or better yet *rehabilitated*? More questions but not many answers.

We must decide if our goal is to find cures and create technical aids and environments which allow us to function basically as non-disabled people or to alter the system so that we can live fulfilled lives as we are — people with disabilities. Maybe we could do both — if we have time

and dollars? People who become disabled often describe themselves as feeling less worthy, unhappy to be dependent and expecting discrimination based on their loss of ability. Many children and adults with disabilities are encouraged to “overcome” their disabilities in accordance with non-disabled standards: the blind singer — *Have You Really Got the Right One Baby?* the paraplegic athlete — *One Man in Motion's World Tour*; the deaf actress/lawyer — *Whose God is Lesser, Marlee?* These are all acceptable images of disabled heroes. Or are they?

While non-disabled people (well, white men in the middle classes anyway) are seen as productive, socially useful and independent members of society, disabled people (along with all the other marginalized members) are seen as dependent, useless and socially rejected, *unless they can act or seem like non-disabled people*. So the basic standard is that of the “normal” person. All attempts at “helping” people with disabilities have been aimed at assimilating them and making them as much like non-disabled people as possible. Disabled people are then further categorized by how deviant they are — measured by scientifically verifiable tools of course. This will help determine how different they are from the “normal” and how much help they need. It will also help with labels — mild, severe, profound, trainable, etc. And these labels make filing systems much easier for the clerks and professionals who use charts and case files.

Given that deviance is unlikely to be completely eliminated, the therapeutic model sets out to ensure that deviance is minimized. Originally seen as a medical issue, it is the clinical, therapeutic model of addressing disability that has resulted in much of the oppression of people

(women) with disabilities. (House, 1981:34). The only way for medical treatment to be scientifically justified and ethically valid is if there is a “normal” way of being that is objectively the best way to live. People who are normal are more socially acceptable and easier to manage. So disabled people are changed, treated, medicated and maybe even behaviorally modified until they resemble this so-called norm.

Maybe we have to stop having measurement and stop having categories or labels that determine relative sameness and difference. I think we can all agree that it is pretty difficult to universally define normality and so it is pretty hard to define deviance. Without a so-called norm we would have no measurement or comparison or even similarities — we would just be diverse.

In an interdependent model of living all people will interact and take responsibilities for each other.

How wonderfully ironic: If only we could get the sighted to see and the so-called normal to really understand, then maybe we would reach some form of equality.

“In matters affecting the disabled, there is no understanding that abnormality and normality are socially defined and, as such are relative terms.”

(Hannaford, 1985:20).

As a relatively major part of our lives, disability can have an overwhelming impact on our lives, but it is only one part. We live as all humans do, as part of a society and our selves are made up of many social constructs like class, gender and age. What makes life so difficult is that all our humanity seems eclipsed by the identification of

disability. But as women with disabilities have found, it is our self-esteem which is so very critical in living our lives:

“We can choose to associate with people who acknowledge and accept all of who we are.

Through this process we begin to incorporate our disabilities into realistic and positive conceptions of ourselves.”

(Browne, Connors, & Stern, 1985:174).

All too often, however, we cannot choose who our friends will be. We are isolated in institutions and segregated into groups by disability and deviance. We might be able to work together in a “disability culture” to develop an identity based on pride and diversity, but how will the “normal” culture adapt to us? Can we expect or demand them to change their ways and adopt *our* standards and *our* images? Maybe it would be better to get them to be *equal* to us rather than us equal to them? We could do it.

Interdependence as a Way of Life: Maybe An Answer

There are so many questions and so many problems that evolve from discussions of equality. Maybe one answer — not *the* answer, but a possible solution would be to consider a way of life based on *interdependence*. Instead of seeing independence as the goal, as the desirable state of being, we can learn to accept our diversity and live together. Sound a little too Utopian? Nirvanic? Edenistic? Walden-like or Orwellian? Let us look at the *equality* issues as they are currently addressed and how the *interdependence* model might work.

If the person with a disability is defined first as dependent — socially, psychologically and economically — then perhaps the hope of equality is in changing this definition.

"The world of the dependent person has been defined historically through the subjective impressions of others and by reference to externalities of action and behavior, rights and duties."

(Weinberg, 1988:260).

Dependence is measured by need, which informs the professionals, and is objectified by bureaucracy. Dependency is considered so negative because those who can walk, talk, hear, and learn without difficulty cannot possibly imagine life without these natural faculties. When a person loses an ability, or witnesses the experiences of people born without these abilities, the perception of dependence is based on *needing* help to do "normal" things. Yet it is the external limitations which handicap people with disabilities. In many instances, being denied one right — such as access to transportation — imposes a limitation on duties — such as employment — all of which are determined not by the disability of the person but by the system. So then, the *need*, or the dependency, is relatively determined by the lack of accommodation or services the system can offer.

The way society discriminates against people with disability can be considered ableism or "disablement." A disabled feminist describes the condition,

"It is about access, social and economic oppression, condescending attitudes and being relegated to Christmas and collection boxes (telethons). It is about being used (and abused) by the medical profession, social work profession and the charity business."

(Hannaford, 1985:21).

Women and disabled people share the experience of being subordinated by societal response to physical characteristics beyond their control. Dependency for women and

people with disabilities may be the same in name but different qualitatively. A woman may depend on a man for adequate income, but the person who is a quadriplegic living in an institution experiences a different form of dependence. Autonomy is valued by feminists and consumers in the disability movement, but when independence is held up as the ultimate achievement, many people with disabilities see futility in trying to be completely free.

The politically correct path is often to favour strength, collective and personal power and autonomy. The juncture of dependence/autonomy is one that has caused some of the problems in our current *equality* debate. It is indeed important to recognize that no woman or man will ever be completely self-

It is the external limitations which handicap people with disabilities.

sufficient or independent of all sources of help and resources. Independence is about control — it's about power over one's own self and environment. Measuring progress towards this absolute goal is not really useful in terms of relating to humanity as a whole.

In an interdependent model of living all people will interact and take responsibilities for each other. Disability would be one personal attribute and might be valued or not but would only be one part of the human. Widespread changes in attitudes would be required and the development and provision of extensive support services and technology would be needed in order to accommodate the needs of all people with disabilities.

Although the less severely disabled people may be easily accommodated into a modern socialist-type

community, we must always include the people who have more severe disabilities. People who are for whatever reason dependent (so to speak) on others for their daily needs must be part of the system of interdependence. Whether for physical, mental or emotional needs, the most severely disabled among us must not be excluded because of their dependence.

So, it is my contribution that although the theme, the dream, the idea of *independence* is admirable, it is in my view *interdependence* that will be our equality — a way of living that allows each person to be valued and to grow without measuring against a norm or standard. Equality will be experienced when we are free of constructs and categories which limit and constrain our identities. When our disabilities are not our destinies.

Our True Equality Lies in Our Humanity

I want to close by sharing some personal thoughts with you. If you happen to not yet be disabled — don't worry, it won't be long. If you don't have a disability, you do not have to be an enemy. We only want you to understand that as people, *we* have rights, choices and feelings, and that for a long time we have been denied our humanity. I used to be angry when a non-disabled person was given a position, or an appointment to a board that was dealing with a disability issue. Now, and only recently, I first determine if that person was the best available person before I make my judgement. I still judge, and form an opinion but disability, or lack of disability is not as important as relative expertise and knowledge. For some jobs, I think having lived as a consumer is a bona fide requirement, and I demand that consumers be involved in decision making and in policy and legal reform — *But we are all human*. As a movement I think we have been

very fortunate to benefit from allies in the not-yet disabled population — those so-called able-bodied people, who for whatever reasons have decided to join in a struggle against oppression. I do not thank them for their help, nor praise them for their advice, for it is *our work* that has brought us this far. But I want to be very clear. I am not a separatist, nor do I believe that we can succeed without the participation of non-disabled people. If my vision of equality is based on interdependence, then they need us as much as we need them. Our loss is their loss, but our gain is also their gain.

My message is do not feel threatened by the achievements of people with disabilities, do not feel suspi-

cious of the contribution non-disabled people are making, because it is in *all of our best interests* to be liberated, to be human. Let us try to reach beyond this artificial construction of normality and be ourselves — whoever we may be.

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Socializing: Problems and Tips

KARI HARRINGTON



*Kari and her mother Ruth share this column. For this topic, Kari decided to write it on her own. Kari has been writing in **Communicating Together** for quite a few years now. She herself has just recently gone through the process of moving out of her family home to Participation House (PH) where she has her own room.*

Until I began to think about writing this article, I never really understood what people meant when they said, "You're not being very sociable." When I got around to asking what 'being sociable' actually meant, there didn't seem to be one exact answer. I made a list to help me understand better.

Being sociable seems to mean:

- being friendly and showing it
- being able to communicate appropriately with new people as well as old friends
- behaving appropriately in different situations
- sharing what you have
- joining in with games and activities that the rest of the group are doing and *not* sitting on the sidelines with a sad face.

While thinking about socialization, I remembered courses I took at High School called "Man in Society" and "The Canadian Family in Perspective." From them I learned that being sociable also means respecting other people — their feelings, their rights and their different customs.

It takes a lot of different experiences and practice all through your life to learn how to *do* the acceptable thing or *say* the right thing at the right time and on every occasion. Learning to be sociable and having others be sociable with you can be a difficult thing for many people. It can be an especially big problem for those who do not have functional speech or cannot move about as freely as others.

When I was younger (and smaller) I had many *opportunities* for socialization with different groups of people. The only thing was, I didn't have any way to *communicate* (other than by laughing or crying and by making a lot of sounds that I *thought* were words, but no one else could understand). When Blissymbols came along, I at last had a way to communicate — but mostly with other Blissymbol users or the people who would take the time and patience needed to read my Bliss Board.

For the six years I was at elementary school, things were pretty good. I worked hard in my special education and regular classes. But it was recess, noon hour and after school that gave me *opportunities* to interact and *communicate* with all the students who went to that school. Many of them were just curious about or interested in the way I communicated and a few of them became true friends.

High School was very different!

As a way of comparing my experiences with those of someone about my age who could talk, I invited Jennifer Hatchaway an attendant and friend here at Participation House, to share and compare some of her High School experiences with mine. Jennifer, by the way is the one who, aside from her other duties, takes time to chat and styles my hair and makes up my face for special occasions.

Jennifer, who is now 22, lived in Goodwood, Ontario, a small village north east of Markham where I live. She had to walk a little way to catch the school bus which took her to Uxbridge Secondary School, about a 20-minute drive away. She was 14 when she started. At first she pretty much stuck to friends she had known since she was four years old, who started school at the same time. After that, her circle of friends just kept growing.

I was 16 when I headed off for Langstaff Secondary School. It was the one high school in the whole large Region of York that was designated to take all the orthopaedic students. It was the only high school which provided health care services and which had an elevator to take

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students from one floor to another. Only one student whom I knew from my elementary school went to Langstaff. He started the year before me! I ultimately became good friends with two regular students, Kelley and Garner. We started out working on projects together and then continued to meet. Garner came to visit me at home and still phones from time to time. However, my circle of school friends was very, very small.

I travelled to and from school on a wheelchair bus which had to arrive and leave the school early to facilitate the unloading and loading of the regular students. There was no opportunity for socialization with the regular students when you had to be in and out of the building before them! Nor was there really any *opportunity* on the bus, except with the drivers. It seemed that, now that I could read and write and had a voice output communication aid (which is the best yet for socializing), the *opportunities* for socialization were getting less.

Lunchtime for Jennifer meant a time for socializing, with eating as a sideline. For most of the orthopaedic students, like me, just the 'eating' and then the washroom were major productions! When I first went to Langstaff, we ate in the same cafeteria as the rest of the student body and we could at least see and hear what was going on around us. Soon after that, it was decided that the 'differently abled' who were increasing in numbers, should eat in their home rooms, to facilitate things for the support staff!

While Jennifer and her friends could converse in the halls as they walked between classes, we had to give our full attention to driving our wheelchairs. When we needed to use the elevator, we had to be accompanied by an aide.

Socializing in the evenings was also much easier for Jennifer than for

me. There were more things she was able to do and, within limits, she was free to go where she wanted to. If worst came to worst for her, there was always the telephone! This is another socializing *opportunity* which is more difficult for those relying on augmentative communication.

Tools and Tips

Jennifer's advice to me now that I'm living at Participation House is:

- take every opportunity there is to go for walks, shopping, to the movies or anywhere
- be willing to participate in in-house activities
- if you have a good idea for an activity, share it with staff
- try to show an interest in what others are doing and try to be helpful whenever you can
- try to look as cheerful as you can (no one wants to start a conversation or socialize with someone who looks very sad or grouchy).

As for communication, one of the best things I ever did since I got my VOCA was to attend the VOCA Workshops being held by Kathy Lee and Nora Rothchild at the ACS within the Hugh MacMillan Medical Centre. There I learned about *chunking* my sentences instead of speaking the whole sentence at once. This helps others to understand the synthesized speech because they don't have to listen to so much at one time and they can be sure that one part is right before hearing the rest. It also keeps the listener's attention on what *you're* saying. If it takes too long for you to type in a message, listeners may become distracted by what's going on around them. Having little words or phrases encoded under one or two strokes which you can stick in quickly when others are talking can help to keep the conversation going by showing your partner that you understand

what they're talking about and that you are interested. e.g., Wow! yes; no; ah huh; uh uh; I like that idea! then what happened? I want that too; who cares; etc. Now, when I go to the VOCA meetings, I am accompanied by Shirley Sweet, a friend and fellow resident at P.H., who also has a RealVoice. Having someone to share the meetings with afterwards makes them all the better.

Another thing I learned was that it is important to pay attention to what is going on in the world around you (and farther away). Then when you have the opportunity to talk and be sociable, you have something to talk about that is of interest to other people.

Jennifer noticed that when I meet new people, they often say "Hi, What's that?" (referring to my VOCA) and I end up talking about my VOCA the whole time. We decided that when this happens, I should just say, "This is my voice synthesizer . . ." and tack a question on to the end like . . . "Do you know someone who doesn't have speech?" Any question that will 'throw the ball back into their court' and make it a two-way *conversation* will do.

When you see someone you would like to talk to, don't be afraid to approach them and introduce yourself. Remember, they might be shy too. Someone has to make the first move. Why shouldn't it be *you*!

Stop the Press!

*I just received the following article from Andrew Murphy, my predecessor as editor of the Living section of **Communicating Together**. The obstacles he faces just have to be added to our thinking about "socialization and independence." I'll share my thoughts regarding Andrew's situation in the December issue — but for now, here's what Andrew has to say.*

Where to from here?

ANDREW MURPHY

Everybody thinks about the future. We all hope and try to plan for a better life. What that means to each of us will vary. I am no different and spend a lot of time thinking about my future. Thinking about finishing my education so I can get a job. Thinking about developing the skills so I can live on my own, with help of course. Thinking about making new friends and staying in touch with my old friends. Thinking about seeing more of the world and how I can make it a better place.

Last year I successfully completed the fall semester at Edinboro University. On the way home for Christmas, I spent a few days in the Pittsburgh Children's Hospital being tested on a new drug called baclofen to see if it would help control the tenseness and spasticity in my body. After the test, I thought it would work. We then had to decide when I would have this pump implanted in my abdomen which would administer the drug through a catheter to my spinal cord.

In January, I returned to school looking forward to the challenges of a new year. Unfortunately, my body didn't cooperate. I became tense very often and was biting my mouth so badly that the people at Edinboro were not able to take care of me. I had to return home. Since we were moving to New Jersey in April, I enrolled at St. Petersburg Junior College and took a course in creative writing which I enjoyed very much.

Since New Jersey was a lot closer to Pittsburgh than Florida, we decided to wait until we were in New Jersey to have the pump put in. On May 19th. I had the operation and stayed in Pittsburgh for observation. The medication helped and my arms

and legs became looser. We returned home with high expectations.

Unfortunately, the catheter "kinked" and the medication stopped getting into my system. I had to go into the Robert Wood Johnson Hospital in New Jersey to have it fixed. When it started working again, my body started relaxing, however, the tenseness seemed to go into my face and I was having even more difficulty opening my mouth. This created more tension at home as we planned for the fall. My hope was to return to Edinboro. However, since I was having difficulty we had to look for other alternatives. We found a transitional living center that seemed as if it might be a good place to learn independent living skills.

I had also enrolled in a two-week augmentative communication course at the Temple University Summer Institute. It was great and I learned a lot about the computer. I made new friends who were dealing with their physical disabilities and still doing great things, and they had good people take care of me. I came home excited about going back to Edinboro and convinced that that was what I wanted to do. However, I still had this problem with the tenseness in my jaw and the biting.

When the course ended, we went to visit a transitional living facility and I had these questions for them:

1. What do the residents do during the day?
2. Where do they go to school?
3. How do they get there?
4. Does the staff help with homework?
5. How many staff are there and how many are on in the morning?
6. What can they do for the residents?
7. Can staff bring residents out anywhere at any time?
8. Do the residents buy their own food?
9. Do residents have to eat at the same time every day?

10. Do residents have to write down what they need done and when?
11. Do the residents like living here?
12. Can friends be invited?
13. Do people come just for TV?
14. Will I learn how to live on my own here?
15. How long do people live here?
16. Can I talk to a resident?

We had a good visit and I was able to talk to some of the people who lived in the facility. They were happy and well taken care of. However, most of them were content with living there indefinitely and weren't looking to move out on their own.

The next day, we went to ISAAC in Philadelphia. It was great to see old friends again. It was great to listen to Mike Williams and hear what they are doing to make the world better for disabled people. It made me even more determined than ever to go back to Edinboro. But still my body would not cooperate. The tenseness in my jaw was getting worse and I was having some very bad bites. I made a decision to stop the baclofen. While we were reducing the amount of baclofen I was receiving, I could feel the tenseness return to my arms and my legs but my jaw didn't get much better. That made me very worried about the future.

I went to see a doctor in Philadelphia to have botulism toxin injected into the muscles in my cheeks. This did relax my jaw and I was able to return to Edinboro. I was sure that was where I wanted to be, but I got pneumonia and had to return home before school even started.

What does the future hold? Where to, from here? If you have any thoughts about how I can get better control of my body, I would like very much to hear from you. Please write to Andrew Murphy, 89 Colfax Road, Skillman, New Jersey, 08558, USA.

§

Facing the Challenge

THE THAMES VALLEY CHILDREN'S CENTRE



The Thames Valley Children's Centre is the major rehabilitation facility for children and young adults with physical disabilities in South-western Ontario. It offers assessment, diagnosis, consultation and therapy for acute and long-term physical conditions as well as speech and language disorders. The Centre is non-residential and sees children both in the Centre and in the community.

The primary goal of the Centre is to contribute to these youngsters' quality of life by helping them reach their potential in terms of independence, self-respect and participation in society. The focus is on the whole child. The case load involves more than 3,600 children and young adults annually.

Judy Lariviere, a recreational therapist, and Sheryl Dedman, an occupational therapist at the Centre organized a Computer Olympics after seeing a presentation of such a program by the Colorado Easter Seal Society at Closing the Gap.

The intense concentration on the faces of Gregory and Sandra could be compared to that of Monica Seles and Steffi Graf, women finalists at Wimbledon. The players were taking

their game very seriously. Where strategy, technique and concentration are key factors in a tennis match, in Sandra and Gregory's situation the sheer excitement of first time competition and the drive to win, overcame the two youngsters. Gregory anxiously sat watching while Sandra had control of the game, the points were accumulating in her favour when Gregory excitedly flashed his hand in front of the computer screen obstructing her vision. "I want to win," Gregory proclaimed in absolute excitement. Unlike Seles and Graff's match, there was no clearly defined winner of this match. Both Sandra and Gregory along with seven other children were all winners in Ontario's first computer olympics.

The Event

Nine children with physical disabilities, aged 7-16, along with their families and friends, participated in the Kiwanis Computer Olympics held at Thames Valley Children's Centre in London, Ontario. The day-long competition was organized to provide the Centre clients with an opportunity to use their computer skills in a competitive, "risk-free" environment with their peers, family and friends. The opportunity to meet and play with other children with physical disabilities is not always an option with children who are integrated into community schools. Caroline Dancel, mother of Gregory, praised the event:

"With the trend towards integration it's great to have events like the computer olympics where Gregory is able to compete with his peers and come out a winner. What a boost to his ego."

Organizers of the Kiwanis Computer Olympics, Judy Lariviere and

Sheryl Dedman, both therapists at Thames Valley Children's Centre, feel that providing children with physical disabilities the experience to independently compete against each other is particularly important due to the lack of programs and opportunities available to them. The children who participated in the computer olympics had severe physical limitations and some were nonspeaking as well. This required them to use power wheelchairs for independent mobility as well as alternative means of communication. The Centre offers assessment, diagnosis, consultation and therapy of acute and long-term physical conditions as well as speech and language disorders. The Computer Olympics fitted well with the Centre's primary goal of helping young people reach their potential in terms of independence, self-respect and participation in society.

Sheryl observed "Often times our children with physical disabilities are excluded from certain activities, leaving the child in the position of a spectator, the passive role. Participation in the computer olympics allowed the children to take an active role, playing the game and trying to win!"

The idea of the Computer Olympics evolved when Judy attended a conference in Minneapolis called Closing the Gap. At this time, the Colorado Easter Seal Society presented their version of the computer olympics called the Adapted Computer Olympics which they have been organizing since 1988. They were eager to encourage others to run computer olympics in their own communities.

Sheryl and Judy spent several months planning the event, a process which involved a great deal of research, dedication and hard work.

As a team member of the Augmentative Communication Service, Judy evaluates and trains clients of Thames Valley Children's Centre in the use of computers for written communication for those who are unable to use the traditional mode of pencil and paper. Sheryl, a team member of the Leisure and Fitness Program, empowers the children to become actively involved in their leisure activities. She sees the exploration of recreational opportunities as helping develop children's leisure interests and skills. The combination of Augmentative Communication Service and Leisure and Fitness programs through the Computer Olympics provided the opportunity to use augmentative communication strategies and techniques in recreation settings. The use of these strategies is a practice that is not common in Ontario and an undertaking that was new to the Centre. The combined efforts and areas of expertise that both therapists brought to the job was supported and enhanced by many staff at Thames Valley Children's Centre and was key to making the event so successful.

The Games

All 17 computer games, some of which were purchased from Colorado Easter Seal Society, had the potential to be controlled by a single switch. This enabled the child to use any body part, be it head, hand, finger or foot, to activate the switch to play the game. The switch works much like a computer mouse or a key on a keyboard, transmitting instructions via specially adapted software.

Assessment of each child participating in the games was pertinent to ensuring that each olympian could play on an equal level with their peers. To do so, Judy matched the appropriate switch to each child's individual physical abilities. Her reason for using a single switch for all of the participants was to ensure

that everyone could perform at their best level. Even if children can use keyboards, when they are excited and trying to hit a little key that is only one centimetre in size, it's easy to miss it. As single switches are larger, it is a lot easier for children to hit the target, enabling them to be faster and more accurate.

Sheryl and Judy involved 25 volunteers on the day of the event. In the spirit of the Olympic Games, 12 of the 17 computer games were medal events. The variety of games included Nintendo's *Duck Hunt*, *Pinball*, *Horse Race*, giving the children the opportunity to excel in various areas while challenging their different skills. On computer systems set up in two rooms, the olympians played computer games against one another for first, second and third-place ribbons and a chance to shine in the winner's circle. There was an official registration table, helium-filled balloons marking the 17 event stations and both volunteers and participants wore the official olympic t-shirt.

Everyone Gains

Sheryl and Judy felt that an important aspect in organizing the event involved exposing the children and their parents to new games, switches and recreational opportunities. Bridget Nother, whose son Franklin participated in the olympics said she found it interesting to see the different types of switches that other children were using. She had not been aware up to this time that there were so many options as Franklin had only been using a head switch. The selection of the games was an important process and computer games that required cooperation, strategy, eye-hand coordination, speed and accuracy were all picked. One parent who participated with his child in some of the non-medal events expressed his delight that the games were so challenging for the children: "It was great to see the

kids having so much fun, but this event is more than just fun. These kids are experiencing real life situations — the thrill of winning, disappointment of losing and importance of team play and cooperation."

Sheryl and Judy were pleased by the overwhelming response and positive feedback to the Computer Olympic games by family, friends and staff. It is surprising for the parents to see their children's reactions in a competitive situation. For many, this was their first experience. They were so impressed by their children's abilities.

The ultimate dream of Judy and Sheryl is to make the Computer Olympics an annual event with more children competing. They would like to target the muscular dystrophy population as these children rely heavily on computers for recreational purposes. The whole idea of the event is to provide people with physical disabilities the opportunity to participate and become involved in recreational activities. Sheryl and Judy can see their event flourishing and they hope there will be competitions in other facilities similar to Thames Valley Children's Centre. They look forward to bringing together the top competitors from all of the centres for a Regional Computer Olympics.

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Have You Moved?

Please remember to let us know your new address. If possible send an address label from a past issue.

Mail to:
Communicating Together
P.O. Box 986
Thornhill, Ontario, Canada
L3T 4A5

The Choice to Be!

NOLA MILLIN



This section is shared by Colleen McGaffey, Rob Haaf and Nola Millin. For this issue, it is Nola's turn.

Rob and Colleen have asked me to write this article on socialization and independence from my *perspective*! Before I begin, I should define what I mean by socialization and independence since these are words with a wide variety of meanings. To me, *socialization* is not just being with people, or another person. It is the act of getting along with people and having an active part within the relationship. *Independence* is not just the physical ability of caring for oneself. Rather it is the psychological ability to make decisions for oneself. Unfortunately, many disabled people think their disability prohibits them from socialization and independence. I am here to say that a disability does not have to be prohibiting because socialization and independence are *choices* each person should have in his or her life.

My Choice

People who know me will testify that I have mastered socialization and independence quite well. Friends call me and complain that I am impossible to find at home! As a speech impaired

person, socialization is not always easy. There are many times I can sit back and let conversations carry on without putting in my two cents. It is rare but I can do it! I have found that I have to be assertive in order to make myself known. When I am assertive, people become familiar with my communication device, then they *want* my input to discussions. Sometimes they get my input like it or not. (I can be outspoken when the need arises!) As I have suggested, socialization is *my own choice*, it is not up to others to socialize me.

Socialization has always been a part of my life. I am an only child so I grew up around many adults. My parents believed that I should know how to behave and how to be sociable; they made sure I learned! My outgoing personality has helped me to express my desire to interact with other people. Despite verbal communication difficulties, I have always made my opinions known. I have never been treated differently because of my disability. This has helped me learn how to make others more comfortable with me. Once people are a little comfortable with the unfamiliar (such as the unfamiliarity of a communication device) then they start getting to know the person.

Peer Activities

My parents allowed me to do age-appropriate activities. I would go to shopping malls with friends as a pre-teenager and teenager. Friends took me swimming, roller-skating, tobogganing, and to many other activities. Even if I could not participate in the actual activity, I was always included in some way such as score-keeping, decision-making or refereeing. In all events, I was always considered a member of the group.

My socialization skills were necessary when I entered a regular

high school system. I had to make my peers realize that I had the same experiences and feelings as they did. When talking about our homework or a dreaded test we were facing, they saw that by listening to me I knew as much as they did. Or, in many cases I lacked the same knowledge they lacked! Once a few students had become familiar with my communication device, which at that time was a word board, then other students also became interested. They found the word board fun to use, which in turn helped them to get to know me. A few of my friends tried using my word board to communicate with me. Again, it was a novelty for them to use it. I did not see this as any insult to me. These friends and I reached the point where we were bad in class. We could "talk" and get away with it! Teachers thought we were working on in-class assignments when in actuality we were talking about soap operas, cute guys, and plans for the weekend. Today, one of my closest friends is a guy who helped carry me up and down stairs during high school. (Accessibility was not one of the school's strong points!)

I now live in my own apartment in a building designed for physically disabled tenants. We have staff in the building 24 hours a day but they only do the physical things that we cannot do for ourselves. *It is up to me to be sociable*. I have a choice to sit in my apartment day and night and to only see staff a few times a day *or* I can go out and be sociable. I have friends down the hall; I have friends all over the city and elsewhere. Again, it is my choice. I have to take the initiative and make friends with people. Once a friendship is made, it is a two-way street. I have friends calling me to talk (yes, close friends are able to understand me over the phone), or to ask me

out, but it comes back to the basic point of being able to be sociable despite a communication difficulty. Actually, I have had one friend say that it was not a communication difficulty on my part, rather a hearing difficulty on his since the longer he was with me, the more of my speech he could understand.

Back to Independence

Independence and socialization are two different topics but they can be closely linked together. I am quite an independent person. My parents raised me that way. I give my parents credit because I have found a lot of parents of disabled children who are very overprotective. My parents allowed me to make decisions even at an early age. Obviously, my mom would not allow me to be foolish. I did not get away with eating junk food instead of eating meals, or wearing shorts in sub-zero temperatures. As I got older, I had more say in matters just like any child and teenager. Fortunately, I grew up learning how to be independent and make my own decisions, for at age 17 I became an orphan. I did not have any natural brothers or sisters to whom I could turn. The bottom line was that if I had been unable to take charge of my life I would have had to move to the United States and live with relatives. I would have missed out on some educational opportunities and a lot of other experiences I have had by staying in Ontario.

Independence, to me, is basically decision-making and the ability to take charge of one's life. It is also the ability to own up to consequences if a wrong or bad decision is made. Although I am dependent on people to care for some of my physical needs, I am still independent. When a staff enters my apartment, I have the ability to instruct the staff about what I need done and how to do it. I instruct people how to make phone calls for me, or to help me with a certain task. Without the ability to make decisions, my independence would be severely hindered.

Since I was raised to be independent, living in my own apartment has been an easy adjustment. I make fairly serious decisions by myself on a regular basis. Being independent does not mean having to make all decisions by yourself. It is knowing *how to make decisions*. I know where to go for advice for certain decisions. Independence is taking charge of the situation and being able to acquire answers to help make a decision. For a person who uses a communication device, this task may be more difficult but it is not impossible.

Throughout the years, I have learned a few tricks to being independent. For instance, when I am seeing a physician, I go by myself after the first visit. For the initial visit, I take someone along but I still communicate to the doctor myself. I type out a letter explaining any problems or asking any questions, then off I go. My doctors do not have a choice but to deal with me directly! I use the same principle for other professionals.

Linking Socialization and Independence

In my life, I can be sociable *because* I am independent. When a friend asks me to do something, I know what that event will involve. We can discuss how I will get there and what help I will need when I am there. If I take the local accessible transportation system, I know that I need to be very specific about how long I can stay since my transportation is restricted. Also, since I control my life, I do not have to ask permission to go out. As well, as an independent person, I am very frank with friends, especially male friends. If we are planning an outing, I openly say, "my bladder can only last x hours." My friend and I will then come up with an action plan. We might end up making a "pit stop" back at my apartment or we might find another solution so that I can go to the washroom while I am out. The bottom line is, I can be sociable because I am independent

enough to explain and make decisions about my needs which helps my friends.

Which Comes First?

I am not sure if I am sociable because I am so independent which gives me the confidence in myself to make friends. Or if I am independent because I am sociable and have friends who support my independence. Whatever the reason is, I have been able to live a fairly normal life (whatever that is!) *because* I have many friends who look beyond my disability. These friends have learned how to cope with such obstacles as stairs! They have joined me as I jump into situations which require me to be in control.

To the Reader

If you have a communication device, *use it!* You have a *choice* to get involved in appropriate conversations and state your opinion. If you are an adult, you do have a say in matters concerning your life. Try asking a few more questions about your care or living conditions. It is great! You really have the *choice* of being independent and sociable despite your circumstances. You just have to make that decision and go for it!

If you are a parent of a disabled child or a professional working with disabled children, teenagers, or adults, encourage as much independence as possible! Think about what you are doing when you overprotect that disabled person in your life. One day you will not be around when he or she is faced with an important decision. What happens then? I have seen too many disabled people in their thirties and forties who do not have any cognitive problems but who are unable to make basic decisions because they have never been allowed to. Mommy or daddy has always been their decision-maker. How about letting that disabled person become a little independent before it is too late? Being sociable and independent are choices you can offer. §

Independence, Interdependence, Participation, Collaboration: Getting Together by Any Name.

Geb Verburg

Geb Verburg has been actively involved in the field of augmentative and alternative communication (AAC) since the mid-seventies. He is currently working as a team leader for the mobility group at the Hugh MacMillan Rehabilitation Centre in a large scale research and development activity funded by the Ontario Ministry of Health.

This column will attempt to strike a straight blow with a crooked stick, an act which according to the scriptures is a divine accomplishment. In my case I probably mean that I would like to make two points and will attempt to illustrate these points by a most crooked and disjointed set of examples. Before stating my points, I must make a small detour regarding terminology. I don't particularly mind whether a person uses the terms independence, interdependence, co-dependence, partnership, participation, collaboration, co-operation or any other co-, par-, or in- terms. The names are not as important as the actions. I believe that we will get a lot more out of any of the states denoted by the above terms if we talk less and do more. The state of living independently, of being able to live independently is one that most of us attain by doing things, acting, choosing, deciding, and of course, by making mistakes rather than by listening and doing nothing.

A Person Must Attain Independence.

The emphasis is on the word attain or strive for or conquer, any word that signifies "reach or achieve through one's own efforts." The problems that people who have disabilities have faced, and still face, in their struggle to attain independence have been the deliberate or inadvertent obstacles that were put in their way by two things: by their disability, and, at least as much and possibly more, by society. The initial obstacles may have been a physical disability, e.g., a child or adult who is unable to speak, unable to walk, unable to manipulate things, unable to see, hear, and so on. But the real, lasting, the far more formidable, and powerful obstacles are the ones put in the way by society. Foremost among them are our expectations, our perception of disability as an illness, our attitudes, and our social mores. And let's not forget, the infamous medical model, the professionals' beliefs and training, the ideologies of care, the structure of our institutions, and our world which is still designed for the average able-bodied (male) person.

The Story of Audrey

The first story: Audrey King, a friend and colleague who has been disabled through polio since age 9, a woman who now holds the position of consumer advocate at the Hugh MacMillan Centre, and who is often invited as a speaker on empowerment, client relations, and community issues, and who was recently interviewed on national television by June Callwood. This same Audrey King told me yesterday that she never said a word all through high school. It was not until she got a job that she dared to speak out and ask questions. It is almost as if having

gotten a job took away the stigma, the inhibition that came with the disability. If this happens to a speaking person how much more might it happen to a child or young adult who is nonspeaking. Would Audrey really have continued in her self/society imposed silence if she had not gotten a job? Imagine how much we all would have missed.

My second point has to do with society's, that is, *our* acceptance of people with disabilities as independent people. We too must attain, conquer, achieve, work at accepting people with disabilities as independent citizens. It is incredibly easy to do, and it cannot be done out of a book, or from a lecture. It can be an experience of a life-time!

I had the good fortune of being able to travel with eight people, three of whom used powered or manual chairs, to Vancouver Island last April. We did the kind of touristy things that people confronted with a large body of water do. We had dinner overlooking the ocean, we walked/rode on the beach, canoed, visited musea, and watched whales. We shared attendant duties and this was something new to me. It was a tremendous eye-opener. I learned more about what it means to live with a severe mobility impairment from these five days of vacation than I had learned in 10 years as a researcher at HMRC. I realize that not everyone can have the pleasure of taking the kind of trip I was able to participate in, but you can have the same experiences working with persons with disabilities. What follows is not meant for regular **Communicating Together** readers, many of whom have long since discovered how equal and fulfilling relationships with people who have disabilities can be. For those new to

disability, don't be afraid to talk, to listen, to get to know persons with disabilities, and I guarantee that you will enjoy and grow tremendously.

Interdependence & Beyond Difference

Next I would like to consider two books by Dr. Al Condeluci. The first book *Interdependence; the route to community* is published by Paul M. Deutsch Press (1991, ISBN: 1-878205-40-4). The second book *Beyond Difference* is in preparation and I had a chance to hear Dr. Condeluci talk about it in Toronto. The title of the 'not-yet' book is important as is the subtitle of Interdependence. Beyond difference refers to the state in which the differences between persons can be transcended. I take that to mean that there will come a time when we no longer see, first, the wheelchair, the blissboard, the touchtalker, the drool on the chin, the odd angle of the head and the flailing arms, the vacant stare of the eyes. We will see the person, the intention burning in the eyes, the joy, the anger, the sadness, the concern, the person first!

Interdependence then, is a book written in a football coach or politicians' style, full of quotes, bulleted lists, and points. The style aside, the book contains a wealth of sound information and observation. It does not contain extremely new or revolutionary ideas. It does contain a vibrant compilation of issues and helpful information.

Condeluci develops his notion of disability using Kuhn's concept of paradigm. He defines paradigm as: "the framework in which we look at a problem and answer the question posed by the problem" (p 43). Paradigm then becomes both the source of problem (i.e., when the framework or context is wrong or too rigid or standard) and the potential solution (i.e., by adopting a new paradigm) such as the "Interdepend-

ence Paradigm" "the paradigm of we" as opposed to independence or "the paradigm of I" (p 88). Interdependence is delineated by contrast to "Medical/Educational and Rehabilitation Paradigms" (p 89). Interdependence "Focuses on capacities," whereas the Medical Educational Rehabilitation Paradigms (or MERP for short) "focuses on deficits." Interdependence "Stresses relationships"; MERP "Stresses congregation". Interdependence is "Driven by consumer"; MERP is "Driven by expert". Finally the Interdependence Paradigm (IP) "Promotes micro/macro"; MERP "Promotes fix or change" (p 89).

The interdependence paradigm looks at a problem from the side of the system, identifies weaknesses in the support structure, encourages the client to identify the problem and attempts to resolve the problem through networks of relationships and support. It sounds simple. It is probably not. But it is a nice angle — a new broom.

Gina and Ray Osborne's Rules for Independent Living

As Shirley and Peter already mentioned in the editorial section of the last **Communicating Together**, Gina Osborne and her husband Ray are parents of 20 children with disabilities. Some of their children have physical disabilities such as cerebral palsy, quadrimembral amputation; others have sensory impairments, developmental delay, or are autistic. What follows are some notes from Gina's presentation together with my interpretation of my acquaintance with the family and many of the children. The Osborne family rule that completely bowled me over was that every child in the family has to be able to get out of the house on their own regardless of their mobility problems. One of the children who was in an institution for 12 years before being adopted was taught to crawl out of the house a foot

at a time. Another child has learned to open a sliding glass door with his lips and cheek and then roll himself out. One youngster without arms and legs can brush his teeth and get dressed with and without his prostheses. The same boy when visiting Wonderland (a theme park) told a staff member: "Don't worry I have nothing much to break."

"The child has to figure it out."

"You have to listen to them"

"They have to be ready."

The expectations in the Osborne household are the same for all children although compliance is not always equal. I visited one evening to pick up videotapes for a study and found the entire family gathered around the enormous kitchen table doing homework. Another time I noticed the familiar rushing about for brownies, soccer, play rehearsals, normal, interdependent, a part of every family.

It sounds pretty cruel to tell a child without arms and legs to make his or her way out of a house. It sounds worse when you realize how much effort, how much coercing, how much bribing, how much encouragement had to go into the accomplishment. True, but it also tells the child, "we believe that you can do it and we will help you." It is an accomplishment on a par to babies taking their first steps, to going to the store alone, to taking the bus to overnight camp, to starting a new school, a first job. It is the stuff that builds egos, experiences that create in(ter)dependence.

Reference

Condeluci, A. (1991). *Interdependence; the route to community*. Paul M. Deutsch Press (ISBN: 1-878205-40-4)

Vital Issues for Independence

PAUL MARSHALL



*As we have indicated in our editorial, Paul Marshall will be beginning his own section, **Paul's Place**, in the December issue. We welcome this short perspective which Paul shared at the recent ISAAC Conference in Philadelphia. Paul is speaking for himself through a means other than his own speech, as he did in Philadelphia. There, Suzanne Clancy, a good friend and past teacher, provided the voice. Here the medium is print.*

My name is Paul Marshall (funny voice for a man). Oh, I forgot, I am nonverbal. This is Suzanne Clancy, she is a good friend and a past teacher of mine. She runs a life skills program at a community college in Hamilton, Ontario, Canada so after this session she might be a good one to speak to.

I remember sitting in a classroom for the handicapped wondering to myself, what will I do with my life? I wanted to know if my life would be fulfilling. At that time I had no form in which to communicate. Every kid, whether handicapped or not, wonders what will their life be like. Sometimes we get wrapped up in thinking that our handicapped kids need more breaks than "normal" kids — more awareness of the trials that

they *must* endure to reach their goals, but not more breaks.

I started in the school system before the legislation mandating the right to education for individuals with disabilities, before the computer age and life skills programs, and before the countless other support programs that we have today. The first stages of the frontier of teaching people that could not make it in the "normal system," of trying to get a good education when the tools were only starting to emerge, was a struggle for both the teachers and the students. Educating a sub-culture like the handicapped population is a demanding task for teachers. Students who want to get a good education so they can go out into a world that offers a life overflowing with opportunities are frequently frustrated. When I went to a "normal" high school, I fell behind, because I didn't have the educational background needed to keep up. With large classes there was not enough time for me answer or ask questions.

At the age of twelve I learned Bliss. This was when my education started. Bliss provided me with a communication tool that allowed me to reach out into the world to begin acquiring the skills which I needed in life. While I was trying to get an education, I moved around trying different systems including a regular high school. During this time, I learned that if I was going make it on my own, I would have to fight each step I took. It wasn't until I took a course called T.H.A.T. (Training the Handicapped Adult in Transaction) that the pieces finally started to come together. Besides being able to upgrade my reading in preparation for taking college courses, it had a built-in life skills unit which was an integral part of my life.

In all, my experiences have led me to conclude that for independence to be a possibility, four vital issues that must be addressed:

- (a) the knowledge of life
- (b) the key called self-worth
- (c) the growing through time
- (d) the outlook of one's self.

The Knowledge of Life:

This step is to realize that every step you make as a person with handicaps outside of the sheltered area of education you will face *unwelcome greetings*. This is a fact both in going on to higher education and in life. The sooner we teach our young people with handicaps this fact, the better prepared they will be. I am thankful at an early age I had the opportunities to see the looks and hurting words from the outside world. At the time it hurt me. But it was a very important lesson to learn at a young age. When I came face-to-face with it in later life, I could deal with it better.

The Key Called Self-worth.

I believe that self-worth starts first at home. Then it comes from mastering things by ourselves. Why did my parents let me crawl? Because they were mean? No! They knew it was important to build my self-worth so I could take that first step towards walking. (Boy! They were sorry because they didn't know where I was from then on.) We must instill self-worth into a person whether they are handicapped or not. Self-worth could be the key beyond all other keys. When people look at me because I am not "normal" (I would like to think it is because I am so handsome! but I don't think so), when people talk loudly to me because they think that I can't hear or understand, when the world keeps

on chipping at my soul, what keeps me from giving it all up? Self-worth is what keeps me going. I know who I am, and I know what I want in life. It really doesn't matter what the world throws at me because they don't know the "real me." You, parents of handicapped, have had "OK, I know both the things that I *can't* do, and the things that I *can* I do?" My outlook on my own life is one of seeing life as a gift. I believe in laughing at myself and making light of my handicap. If you smile, you walk upright in the world. If you are downcast then the world will pass you by.

If you are asking me is there any hope for you to get a college education, my answer is yes. Sure, there will be hardships and trials to master. But if you are willing to *go for it* then the battle is half won.

§

Empowerment and Self Advocacy

MICHAEL WILLIAMS



Michael Williams is well known for his wit and expressive skills. He has been working in the forefront of the disability rights movement for more than twenty years. When he moved to Berkeley, California in 1969 he became heavily involved in the pioneering Center for Independent Living. Here he discovered his

passion for writing about disability issues and since then, many of his articles on disability have been circulated around the world. Michael, his wife Carole and his seven-year-old son Malcolm were busy participants at the ISAAC Conference in Philadelphia. Michael gave three presentations, one which was co-presented with his wife, Carole. Malcolm explored all the events and took the spotlight by selecting the winners of the ISAAC Draw to raise funds for consumers to attend the 1994 ISAAC Conference in Maastricht, The Netherlands. (A reminder to all readers to begin saving now!)

I've been asked to speak on two of the hottest buzzwords of the 90s: *Empowerment* and *self-advocacy*. Well, I've got news for you. Back in the 1950s when I was making my way through the teen years, these ten dollar terms were known as independence and self-reliance. They were peddled to the drone of countless mundane pop tunes, and supported by that smiling man in the White House, Dwight David Eisenhower.

Of course, having a disability, I had little independence or self-reliance. Once, when I was about four, I was playing in a sandbox with a friend. I was hogging the shovel and my friend decided to give me an object lesson in the art of sharing. He snatched the shovel from my hand and hit me over the head with it cutting me rather badly.

From that point on my mother took over management of my alter ego. Whenever I entered a new area of experience, my mother would always pave the way for me. I always let her. After all, it was so much easier than doing it myself. I couldn't talk, she was very articulate. She always said the things I would say.

This had a subtle but profound effect on my personality. When you have someone representing you at the bargaining table of life, all you have to do is sit back and reap the benefits. As

a result, I didn't develop my sense of anger and outrage until recently. All I had to do was sit there and be Mr. Nice Guy while my mother took care of the flack coming down on me. It was not only my mother. The community as a whole (therapists, doctors, educators, relatives, neighbors and friends) all cooperated in this insidious effort to protect me from real life.

Watching my seven year-old son grow up has given me valuable insights into empowerment and self-advocacy. These qualities must begin early in life. Malcolm, my son, has been able to dress himself since the age of three. He has several dresser drawers full of clothes which he has control over. He gets up in the morning and puts on whatever he wants. Sometimes my wife and I take one look and a vigorous discussion ensues. It would be much easier to buy all his clothes off the sale table at the local department store and tell him what to wear each day, but this would not do Malcolm any good.

When I was a teenager back in the fifties, my mother was still buying my clothes for me. I had no clue as to my shirt size, my pants size, nor my underwear size. I certainly didn't have any concept of style and fashion, because I seldom went to the department store.

Today, I can buy clothes for myself, and select clothes to wear each day, but I don't enjoy doing it. I am not like my son for whom getting dressed each day is an adventure in sartorial splendor.

Empowering a child with a disability creates much more work for the parents; it is much easier to do everything for them and be done with it especially if there is a communication problem. But this creates a set of psychological and social problems that the disabled adult will have great difficulty dealing with later in life.

§

Parents and Symbols: Charting the Language Pathway Together

SHIRLEY MCNAUGHTON

Only two pages and so much that could be said! As promised, the focus for this SymbolTalk is *learning to read*. I bring to the topic the perspective I presented and some of the recurring ideas I heard at the ISAAC '92 Biennial Conference in Philadelphia this summer. Both the conference, Aug. 7-11 and the ISAAC Research Symposium, Aug. 12, 13 provided thoughtful sessions on literacy which stimulated lively discussion and promises of further study and sharing. We have much learning to look forward to in this area.

Language Pathway to Reading

Let's return to the pathway metaphor for language, which I derived from the work of Daniel Keating, Catherine Snow and Nicola Nelson and described in the June SymbolTalk. The pathway analogy fits well with the commonly held view that was mentioned frequently at ISAAC — *the ability to read must be considered within a broad understanding of language and literacy*. Each strand of the pathway has an important part to play in learning to read and write. As a strand interacts with others, so it influences the whole learning process.

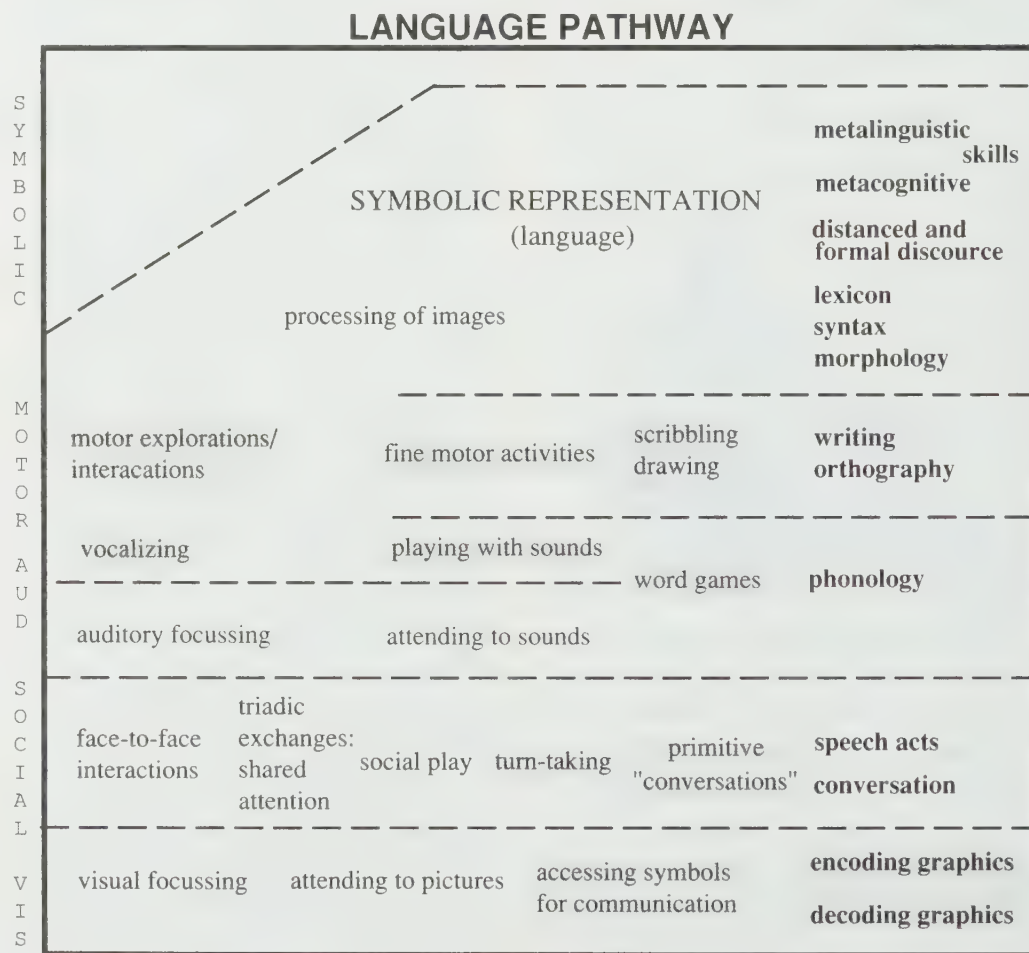
The "Language Pathway" schematic is a simplified portrayal of the "Integrated Pathways to Development" which I presented at an ISAAC Conference session shared with Peter Lindsay, Veronica Ellis and Margaretha Vandervelden, entitled "A Model of Literacy Acquisition in the AAC User."

The dotted lines depict not only the various domain pathways but as well, the interaction between them. All of the language skills listed in the right column contribute in some way to learning to read. All of them have their beginnings in the young child's growing visual (vis.), social, auditory (aud.), motor and symbolic development. The shading indicates the areas in which the young child who uses graphic symbols for communication differs from the speaking child.

Of strong importance are the *motor* (including oral-motor), *social* and *visual* domains. It seems obvious that the physically able child has the advantage of many more motor and speech learning experiences. But recognizing that there are differences along the developmental paths between children who are

able-bodied and those who have speech and physical impairments is only the initial step. We must then ask: "Does it make a difference to their learning to read?" and "What difference does it make?"

The work of Jerome Bruner (1966) provides a structure for talking about the child's changing *representational* abilities. The representational stages are shown below within the symbolic and motor domains. Representational abilities become more powerful as the child develops from *motor explorations and interactions*, through the *processing of images*, to *symbolic representation (language)*. The symbolic strand of the pathway leads to all the higher level language skills which contribute to successful reading. Our further questions must be: "What effect is there upon symbolic development from the use of



various types of symbols for communication?" and "Can the experiences gained by children who use visual symbols instead of speech, compensate to some extent for the limitations they face in other domains?" I presented the need for enquiry into this area at the ISAAC conference. I look forward to the findings from future research studies which tackle this issue.

Independence

There could not be a better key word to summarize the major challenge I took from the literacy sessions at the ISAAC conference than the first word of this issue's theme — *independence*. When relating the concept to language development, *independence* for children with severe speech and physical impairments requires a cognitive rather than a physical emphasis. Control over the expression of their language must be achieved as children travel the language learning pathway.

Through their talking, speaking children *independently*, develop abilities which help them progress in many domains. Most importantly for beginning reading, they are preparing themselves for *phonological* recoding — the process by which sounds are associated with letters, supporting the child's decoding of new words. For speaking children, the phonological pathway contains many early experiences which help them gain knowledge about the sounds of speech. Children with severe speech and physical impairments are deprived of many of these learning opportunities. Other compensating experiences are being discovered, however, to help these children along this strand of the language pathway. Although the early motor and auditory activities of *vocalizing, playing with sounds, auditory focussing, attending to sounds and word games* which typically precede phonological recoding cannot be the same for the young

nonspeaking child there is now a hopeful alternative.

Several presenters at ISAAC shared their observation of increased phonological abilities in children who have used synthetic speech. They called for further investigations into the effects of using different types of voice output communication aids upon the development of phonological recoding skills. It is an area of enquiry that shows high promise. Each child's *independent* control over his or her voice output device so that the child can determine the amount and type of "vocal play" would seem to be an important consideration. With our focus here upon symbols, we must ask "How can this independence be facilitated cognitively through the symbols available to the child?"

Independence can, of course, also be considered from a physical control perspective. Ways are being found by innovative instructors for children with severe speech and physical impairments to gain independence in choosing and in deciding the speed and frequency with which they read materials. Parents are being urged to give preschoolers control over which stories they wish to have read and how many times a story will be reread. Ways are being provided for the child to be involved actively in the reading process through innovative computer software programs and through creative teaching strategies by instructors.

In Summary

ISAAC reinforced that:

- we *are finding ways* to do much better at teaching children who have speech and physical impairments to read;
- we *must learn to better observe* both the children's strengths and their weaknesses;
- we *must recognize the potential value of synthetic speech* in refining children's auditory skills;
- there is growing interest in *examining all of the factors* affecting the reading acquisition of young children who use AAC systems not just in isolating one

or two variables;

- to date, *little attention has been given* to the possible relationship between the type of symbols a child uses and his or her reading abilities.

Be thinking as you read further:

- What language domains are being examined?
- Might the symbols be making a difference to the literacy learning process?

Recommended Current Papers:

Methodological Issues in Research in Augmentative and Alternative Communication. Proceedings of the Second ISAAC Research Symposium in Augmentative and Alternative Communication, Philadelphia, Aug. 12-13, 1992:

Koppenhaver, D.A., Coleman, P.P., Steelman, J.D., & Yoder, D.E. The Emergence of Literacy Research in AAC: Methodological Issues and Research Priorities.

Smith, M.M. Literacy and AAC: Methodological Issues and Research Priorities.

Smith, M.M. (1992). Reading Abilities of Nonspeaking Students: Two Case Studies. *Augmentative and Alternative Communication*, 8, (1), 57-66.

Be Watching For:

Topics in Early Childhood Special Education and Learning Disabilities Quarterly for two emergent literacy intervention studies by David Katims;

Brain and Language for a phonological study by Beth Foley;

Topics in Language Disorders, 13 (2), 1993, for literacy-related papers by Patsy Coleman and P.J. McWilliams on emergent literacy, by Beth Foley on language/literacy relationships, by Janice Light and David McNaughton on attitudes and expectations, by David Koppenhaver and David Yoder on school-aged children and by Shirley McNaughton on graphic representation systems and literacy learning.

Reference

Bruner, J. (1966). On cognitive growth. In J. Bruner, R.R. Olver, & P.M. Greenfield (Eds.), *Studies in cognitive growth* (pp. 1-29). New York: John Wiley.

¹ For a copy of the "Integrated Pathways to Development" model and the handout from her ISAAC 1992 Biennial Conference literacy presentation, write Shirley McNaughton, c/o Sharing to Learn.

§

A Letter from Carol Lynn Katsios Vancouver, British Columbia

I was pleased to read the article by Sachi Tamura and Susan Webber titled "vulnerable" in the March 1992 issue of **Communicating Together**. This is a much more common problem than most people realize, and it is a serious cause for concern which must be brought to everyone's attention.

While it is true that people with disabilities, especially nonspeaking persons, are very vulnerable to sexual abuse, there is another side to this coin that must be looked at as well. *We are all vulnerable human beings*, whether disabled or otherwise, and social responsibility is a two-way avenue.

Many disabled people have spent many hours of their lives over many years trying to dispel myths and stereotypes about people with disabilities. Unfortunately, much of the public remains unaware and unconcerned. The average person in our society does not view a disabled person as a wife, mother, husband, father, computer programmer, writer, or manager. Rather, they are more comfortable with the old, familiar stereotypes of a disabled person as an asexual, poor, helpless, pathetic creature to be pitied.

Within such a context, it is all too easy for persons who have a disability to take advantage of those around such as their attendants or drivers. And these individuals may not be able to defend themselves when attacked by these myths and stereotypes. This problem also is a serious cause for concern. It can happen much more often than people realize.

There are many reasons why a person with a disability might accuse someone falsely of sexual abuse — jealousy, revenge, instability, loneliness, insecurity, frustration — in short the same reasons that would cause anybody to accuse someone falsely of sexual abuse. And who is more likely to be believed — the disabled person. People listening to him or her tend to see a stereotype rather than a human being. In these days of human rights, people are understandably anxious to protect the innocent, the oppressed minorities. They are sorry for those they feel are helpless and vulnerable.

People who work with physically disabled individuals are often dedicated, empathetic people who have learned to see beyond the wheelchair to the person in it. Because

of the intimate association that often exists between a care-giver and a consumer, everyone who works with the disabled are in a vulnerable position. Care-givers, and not just front-line staff, have been known to be accused falsely of stealing money, food, or other possessions from consumers, as well as being falsely accused of sexual assault in every conceivable form. Occasionally, it has even resulted in an innocent person being convicted of a crime he/she did not commit.

The goal of the many people who have disabilities is to create a public awareness that will result eventually in the acceptance of disabled persons into the community and the workplace as equal human beings. To take advantage of being disabled, to accuse someone falsely of sexual abuse works against that goal. It reinforces and strengthens the old stereotypes and myths in the public mind. It unravels years of hard work and dedication by many who have strived to make better lives for themselves. It not only destroys an innocent person's reputation, it destroys the accuser's own credibility, and as a result, the credibility of other disabled persons. It can force badly needed care-givers into other fields of employment.

But the real danger to society lies in the long-term effects of stereotypes that are still alive, and can be reinforced in the minds of so many people if just one disabled person acts irresponsibly.

Society is an interwoven fabric of threads called human beings, each with their strengths and weaknesses. Each one is unique, regardless of age, race, religion, or disability. Each is necessary to keep the fabric whole.

If we continue to perpetuate, or allow to be perpetuated, stereotypes that cause us to pick out and separate threads that don't seem to fit — to pick holes in our fabric — someday we will wake up to realize that, like moths, we have eaten away our fabric, and torn apart our society.

Freedom is something to be desired. Freedom is something worth fighting for. But freedom and equal rights carry with them a responsibility that must be used wisely by everyone.

Only when we all work together to make this realization a reality will we strengthen the fabric of our society, and make it a better place for everyone.

Editor

Communicating Together

Easter Seal Communication Institute
250 Ferrand Drive, Suite 200
DON MILLS, Ontario M3C 3P2

Dear Sir:

I am writing to you on behalf of several of our residents at the Natanya Residential Home for the Disabled in Israel, who are interested in corresponding with people in Canada.

Our Home is a residential center for young handicapped adults, ranging in age from 18 to 50. We have about 60 residents, all intellectually normal, and many of them use

a computer for word processing. One of my tasks as a Speech Pathologist is to assist them in using the computer as a tool for communication, particularly communication with the "outside" world.

Should any of your readers be interested in corresponding with our residents, we would be delighted to hear from them.

Thank you.

Sincerely,

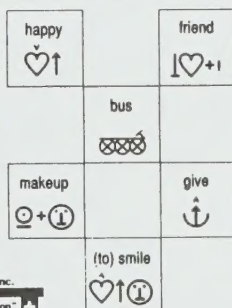
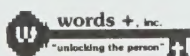
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